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ABSTRACT

This brief paper summarizes three papers and a response presented at a symposium examining longitudinal comparison studies of federally funded community mental health services (CMHS) for children and their families. Emphasis was on comparing the system of care approach to a more traditional approach. The symposium provided an update on the status of the studies by: (1) addressing the policy implications of these studies; (2) providing an update on outcomes study data collected; (3) reporting on data collected on families' services experiences; and (4) comparing service system development between CMHS-funded and comparison communities. The paper provides summaries of the following presentations: an introduction by E. Wayne Holden, Chair; an overview on the current status of the longitudinal comparison studies by Rolando L. Santiago, Director of Program Evaluation in the Child, Adolescent and Family Branch at the Center for Mental Health Services; a report by Mario Hernandez, University of South Florida, on the development and results of the Systems of Care Practice Review, a measure implemented in the Phase I comparison studies to evaluate families' experiences with care; and a report by Ana Maria Brannan of ORC Macro on preliminary results of systems level assessments conducted in early 1999 across the six communities participating in the longitudinal comparison study. Discussion by Trina W. Osher, a parent and advocate, raises questions about the generalization of the findings (which supported the system of care approach) and urges greater refinement of evaluation systems. (DB)

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Symposium Overview

Preliminary Report on the Longitudinal Comparison Study of the National Evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program

Chair
E. Wayne Holden

Discussant
Trina W. Osher

Presenters
Rolando L. Santiago
Mario Hernandez
Ana Maria Brannan

Introduction

E. Wayne Holden

The longitudinal comparison studies, initiated in 1997, are a component of the National Evaluation of the Comprehensive Community Mental Health Services for Children and their Families Program. The purpose of the comparison study is to address the primary question: "Do children with behavior and functioning problems improve more when served with a system of care approach compared to a more traditional approach?" Several secondary questions have also emerged in these studies, including what are the differences in service system development between Center for Mental Health Services (CMHS)-funded communities and their matched comparisons, and how do families' service experiences differ in systems of care compared to other communities. This symposium provided an update on the status of the longitudinal comparison studies by: 1) addressing the policy implications of these studies, 2) providing an update on outcomes study data collection, 3) reporting on data collected on families' services experiences, and 4) comparing service system development between CMHS-funded and comparison communities.

Policy implications of the longitudinal comparison studies were highlighted in opening remarks by Michael English, Director of the Division of Knowledge Development and Systems Change in the Center for Mental Health Services. These remarks provided a context for the symposium by highlighting current Federal initiatives in children's mental health services and the need for evaluation data to continue to support the expansion of community-based services.

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Review

Rolando Santiago, Director of Program Evaluation in the Child, Adolescent and Family Branch at the Center for Mental Health Services provided an overview on the current status of the longitudinal comparison studies. Following the presentation of background information and a review of relevant literature, the current status of the longitudinal comparison studies was briefly summarized. Since 1997, over 1,000 families have been recruited from 3 system of care and 3 matched comparison communities to participate in Phase I comparison studies. Each of these six sites has participated in a systems level assessment and a family experience sub-study. Service and costs data are currently being compiled. Follow up outcomes data collection for these studies will be completed in December, 2000. Preliminary analyses of intake data suggest that there are some differences in demographic and clinical characteristics at intake that will need to be addressed in outcomes analyses. Data completion rates for the Phase I comparison studies at the 6 and 12 month outcome assessments are within the acceptable range. Two comparison studies were also initiated in the Fall of 1999 involving two system of care sites that were initially funded in 1997 and two matched comparison communities. A slightly different outcomes data collection protocol has been implemented and a special study is being implemented that examines interactions between service delivery personnel and families for several months after services are initiated. Treatment effectiveness studies that focus on measuring the specific effects of evidence based interventions within systems of care are being planned for grantees funded in 1998 and 1999.

Mario Hernandez, University of South Florida, reported on the development and results of the Systems of Care Practice Review, a measure implemented in the Phase I comparison studies to evaluate families' experiences with care. A direct assessment of service experiences at the practice level was included to determine whether system of care principles were being directly expressed in practice-level interactions among service delivery personnel and families. System of care principles may be fully expressed at the overall community and specific agency levels, but incomplete infusion of these principles

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into practice interactions will limit tests of the overall effectiveness of the approach. An assessment of service experiences at the individual child and family level allows the testing of potential differences between system of care and comparison sites and the examination of how service experiences overall may influence the relationships between service delivery systems and outcomes. Case studies were used as the approach to evaluate service experiences due to their unique applicability for investigating social phenomena in real world settings. The specific case study protocol for this study (University of South Florida, 1998) provided both qualitative and quantitative information about families' experiences at the interface between services provided and the needs and strengths of the children and families.

Samples of families were selected from system of care and comparison sites for participation in the systems of care practice review protocol. The protocol for each family participating in this part of the longitudinal comparison study consisted of multiple data collection components including document review, primary caregiver interview, child interview, formal provider interviews and informal helper interviews. Interviews and document reviews were conducted by data collection teams who typically conducted a 1- to 2-week data collection site visit to obtain information for all participating families. Information was combined across the document review and interview data using a sequential analysis process that included coding, sorting, rating and examining the information collected by the data collection team. The primary domains that were assessed included: 1) child and family, 2) community, 3) cultural competency and 4) impact. Preliminary results revealed significant differences between samples from systems of care and comparison sites across the domains assessed by the practice review protocol. All differences indicated higher levels of system of care principles in CMHS-funded sites.

Ana Maria Brannan of ORC Macro presented the preliminary results of systems level assessments conducted in the Spring of 1999 across the six communities participating in the longitudinal comparison study. The conceptual model underlying the systems level assessment protocol and the procedures for conducting the visits were reviewed. Quantitative results from site visits conducted in the Spring of 1999 were presented along with qualitative data to enrich the understanding of differences detected in levels of system development between systems of care and their comparison communities. In general, funded systems of care received higher scores on average than systems without funding, especially in the infrastructure domain. Across the longitudinal comparison study pairs, interagency involvement and community-based service delivery were areas of greatest difference with CMHS-funded systems of care displaying higher levels of development in these areas. Family involvement, however, was a distinguishing feature in only one of the three longitudinal comparison study pairs. Evaluating the relationships between systems characteristics and outcomes awaits the completion of outcomes data collection in early 2001.

Discussants' comments focused on the strengths and weaknesses of the longitudinal comparison study and the implications of these results for the field of children's mental health services more generally.

Discussion

Trina W. Osher, M. A.

My frame of reference is that of an advocate and parent of children who use mental health services. I subscribe to the values and principles of the system of care — though my own family did not have the opportunity to benefit from such a system directly. The system of care is not a treatment or services, but an structured approach to service design that we assume and hope makes it easier, more efficient, and more effective to deliver services for children who have serious emotional disorders and their families. Families who experience systems of care tell me that they like them, that they think they are better for their children. Personal testimony to the efficacy of a systems of care approach is great, but, in a political arena where I seek support and funding for children's mental health — and systems of care specifically — I need some hard evidence to convince others.

Do these studies help me out? Frankly, I'm not sure! I confess to finding the case study methodology of the System of Care Practice Review family friendly and appealing — though it does seem to require a

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great deal of effort and cost a lot to use. The findings also appeal to me — families in grantee communities where there is a highly developed system of care report having had a better experience; and in particular that they were included in planning services and that the approach was strengths based. It is also good news that families felt their children made greater improvements in the grantee communities.

But given the limitations of the study I hardly think the findings can be generalized. Furthermore, without linking the process of receiving services to outcomes and their cost, I doubt that these findings are powerful enough to influence national policymakers.

The system development comparison shows that there are in fact measurable differences between systems of care and traditional service communities — particularly with respect to infrastructure and community-based programming. This too is good news. But it is still not sufficient to impact policy makers. I confess to being disappointed to learn that family involvement was a distinguishing feature in only one comparison pair. Why is this so? How is this grant community different from the others with respect to the features that support family participation? I hope that this does not mean that we think we can build systems of care without significant family involvement. My understanding is that the system of care *must* have families meaningfully involved in governance and decision making about development, implementation, and evaluation of such systems.

This study raised some further questions about its implications. Do these results about family involvement mean that there needs to be a more intensive effort to include families as full decision making partners in systems of care? Do grant communities need help recruiting, training, supporting, and retraining families on their team?

Like any ordinary non-research person, I look for a message in the medium. In this case, I look for pictures or images created by the graphs presented. While the curves for the grantee communities were generally above the curves of the comparison communities, the shape of the comparison curves was similar for some of the pairs. This suggests to me that when federal grant resources are added to a community, they enhance existing services to get more of the same services without actually creating a change in the infrastructure, services, or outcomes. My own view of the system of care approach is not just that it involves a larger number of the elements commonly found in communities, but that it arranges and uses these elements in different ways; systems of care break down barriers and create new service delivery systems. Do these findings mean that there is something (structural, political, economic, or social) operating in all six of these communities that the system of care approach taken by the grantee communities is not powerful enough to overcome? Or does this mean that the instrument or the analysis tools are not capable of discerning significantly meaningful differences in infrastructure? What about conducting comparisons within the same community? Since grant funding is limited, not all children who might be eligible would be enrolled in a system of care. Concerns about the grant influencing other community structures and, therefore, contaminating the comparison may not be all that important since, as these comparisons show, systems of care take a long time to develop. Indeed, none of the grant communities in these comparison studies had fully achieved all dimensions of a system of care.

How children and their families experience systems of care and how communities build them is important to understand and I applaud researchers in the field of children's mental health for contributing to this understanding. But this is still early, pioneering work. Once these measures and approaches are refined and used further, the next step will be to relate this work to the changes that occur in the lives of the children and families served. Even a true believer in systems of care like myself wants evidence not only that such systems exist, but that they make a significant difference. I sincerely hope that the research community succeeds in finding the significant and distinguishing features of systems of care and further finds that these result in better outcomes that are cost effective and satisfying for children, families, providers, and communities.

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